

Quality of Life for Patients with Chronic Illness

September 15, 1999

The FRIENDS of the National Institute of Nursing Research held its third of three Congressional breakfast briefings this year on September 15, 1999. The topic was Quality of Life for Patients with Chronic Illness. FRIENDS, an independent, non-profit organization, supports the NINR by promoting public awareness of the role of nursing research in advancing health care practice in the United States. Those attending the briefings included members of Congress and Congressional staff, nurse researchers and administrators, and members of public and private organizations with a special interest in the topic.

Diane McGivern, PhD, RN, FAAN, President of FRIENDS and head of the Division of Nursing, New York University, provided brief welcoming remarks and thanked Senator Charles E. Schumer (D-NY) and Congresswoman Louise M. Slaughter (D-NY), for sponsoring the event. She also thanked the corporate sponsor, Bristol-Myers Squibb.

Patricia A. Grady, PhD, RN, FAAN, Director of the NINR, provided introductory remarks. She underscored the significance of the increasing incidence of chronic illness across all age groups in the society. Furthermore, those facing the end of life frequently have endured lengthy chronic illnesses in the prior years and months. The NINR research focus is on management of symptoms, such as those associated with HIV/AIDS and cancer, helping patients make treatment choices that meet their quality of life needs, and providing family caregivers with skills training and technical support that will improve the health outcomes of their ill relatives while maintaining their own health and quality of life.

THE RESEARCH

Improving Clinical Response and Quality of Life in Persons Infected with HIV, Judith A. Erlen, PhD, RN, University of Pittsburgh School of Nursing

Dr. Erlen explained that the concept of quality of life encompasses the patient's entire well-being, including a broad spectrum of physical, social, psychological, and spiritual factors. She is Associate Director and researcher at the Center for Research in Chronic Disorders, one of nine Centers of varying research focuses supported by NINR. Her particular emphasis is on quality of care and quality of life of patients with HIV infection. Most recently, she is concentrating on adherence to antiretroviral therapy.

Because of recent, significant advances in the management and treatment of HIV infection, many people with HIV now live with the illness rather than die from it. The current antiretroviral therapies that extend life, however, also affect the quality of that life. To successfully combat the disease, the regimens require strict adherence, which also requires substantial adjustments in daily living. Side effects of the medication are another important issue.

Dr. Erlen's research on quality of life with hospitalized and community-dwelling patients with HIV shows that quality of life varies with disease progression. A preliminary study using a technique called "life review" demonstrated the potential of this intervention to improve quality of life and purpose in life. In examining quality of life in a sample of persons taking antiretroviral therapy, Dr. Erlen found that these medications offer an enhanced quality of life, as well as a second chance at life. Even though taking these drugs complicated their lives, the participants believed that they were better off with the drugs and continued to take them. Another study has demonstrated the value of social support when taking antiretroviral medications. She is currently using a habit training and problem solving intervention to promote adherence in order to improve clinical outcomes, such as reduced viral load, increased CD 4 count, fewer hospitalizations, and fewer opportunistic infections, as well as increased quality of life. Research on this intervention, which is in the early stages, also has the potential to reduce health care costs.

Improving Survival in Cancer Patients After Surgery, Ruth McCorkle, PhD, RN, FAAN, Yale University School of Nursing

Dr. McCorkle, who was the former Director of the Center for Advancing Care in Serious Illness at the University of Pennsylvania before she moved on to Yale, discussed a series of five randomized clinical studies that focus on the role of the advanced practice nurse (APN) in oncology and on the quality of life and survival for cancer patients and their families.

- Study 1 tested the effects of home nursing care over eight months for three groups of patients with progressive lung cancer. The first group received specialized oncology home care from APNs specializing in adult health; the second group received standard home care from nurses at the baccalaureate level; and the third received care from staff at a doctor's office. The two home nursing care groups had less distress and were more functional up to six weeks longer than the group that received office care.
- Study 2 was an extension of study one and followed the spouses of the lung cancer patients 25 months after the patients' death. The study looked at whether the specialized intervention exerted a positive influence on bereavement, as measured by psychological distress among the survivors. Findings showed that the bereaved spouses receiving the APN intervention evidenced reduced overall psychological distress during the critical period of 13 months after the home care intervention, compared to controls.
- Study 3 examined the impact of post-hospital home care on two groups of cancer patients - one newly diagnosed with cancer, and the other with recurrent cancer. Both groups (early and late stage cancer patients) who received home care from APNs demonstrated statistically significant improvements in their mental health and functional abilities, compared to controls.
- Study 4 compared the length of survival of the early-diagnosed post-surgical older cancer patients in Study 3. The newly diagnosed patients treated surgically for a solid malignancy and receiving the APN specialized home care have so far lived longer than the usual care patients. The survival advantage of those with late stage cancer has been particularly significant.
- Study 5 tested the effects of an APN nursing protocol on quality of life for older cancer patients. The burden on the family was also measured at the time of hospital discharge and 3 and 6 months after surgery. Overall, the quality of life of patients in both APN and usual care settings improved. Findings related to certain subgroups, however, indicated areas in need of further attention. The unmarried males in the control group reported significantly higher levels of symptom distress and may be at high risk for continuing problems. In both groups, caregivers with their own physical problems also appeared at risk for psychological morbidity. Home care referrals, therefore, should include assessments of the health of the caregivers.

Taken together, these studies provide clear evidence that APNs specializing in oncology make a significant difference in positive patient outcomes, both in terms of longevity and of quality of life with a chronic illness, such as cancer, and in caregiving and bereavement of family members.

CHALLENGES

As the U.S. population ages, chronic disorders will affect an ever-growing segment of the population. Pressures to control costs and move health care into the outpatient arena underscore the need to develop better strategies to manage chronic disorders, prevent complications, and maintain or enhance the functional abilities of those who are ill. Answers to key research questions will promote optimal care and quality of life for chronically ill patients. These include:

FOR HIV PATIENTS RECEIVING COMBINATION ANTIRETROVIRAL THERAPY

- Determining what is the best time for initiating this medication therapy.
- How can side effects of the medication best be managed.
- How do treatment regimens affect quality of life and how can life adjustments be made.
- What is the relationship between quality of life and disease progression.
- Which interventions are best to maintain or improve quality of life for these patients.

FOR POSITIVE QUALITY OF LIFE OUTCOMES AND SURVIVAL IN CANCER PATIENTS AND FAMILIES

- How can caregiving capabilities of informal caregivers be assessed effectively, particularly when they may be ill.
- How can APN expertise and consultations be more effectively utilized by other nurses.
- What are the most effective ways to incorporate family or friend caregiver issues into the hospital discharge planning process to ensure a smooth transition from hospital to home and the recovery of the ill patient?